Community AIDS Initiative
Survey Results on Services for People Living with HIV/AIDS in Hamilton

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS i
EXECUTIVE SUMMARY ii
1.0 Introduction 1
2.0 Background 3
3.0 Methodology 11
4.0 Survey Results 13
5.0 Agency Service 15
6.0 Services 17
6.1 Service To HIV/Aids Population 17
6.2 Services Specific To HIV/Aids Population 20
6.3 Accessing HIV/Aids Services 21
6.4 Gaps In Services 22
6.5 Developing Services 23
6.6 Organization Requirements For New Services 25
7.0 Interested In Receiving More Information 27
8.0 Closing Comments From Respondents 29
9.0 Analysis Of Results 31
10.0 Summary And Conclusion 35

Selected References: 37

Appendix:

Questionnaire.

EXECUTIVE SUMMARY

This report describes a study carried out to gather up to date information on the current service trends and needs of people living with HIV and AIDS and their caregivers. It has been prepared by the Social Planning and Research Council of Hamilton-Wentworth for the Community AIDS Initiative project.

To provide context for the study national trends were reviewed. They indicate that HIV rates in Canada are still increasing. Those becoming infected with HIV are younger and the spread of this disease is increasing dramatically among injection drug users. Incarceration is an important risk factor in acquiring HIV, aboriginal peoples are over-represented in groups most vulnerable and women represent an increasing percentage of new HIV cases.

The estimated number of individuals living with AIDS in Ontario as of June 1999 was 1,759 persons. The number of individuals living with HIV was estimated at 8,484 persons.

The estimated number of individuals living with AIDS in Hamilton-Wentworth as of June 1999 was 56 persons. The number of individuals living with HIV was estimated at 269 persons in Hamilton-Wentworth. A mail out survey questionnaire was developed and mailed to 115 agencies in May 2000. It was designed to gather information about the nature of community services available to people in the community with HIV and AIDS and their caregivers. The survey also asked for information about perceived gaps in services and what would be needed to address these gaps.

Organizations responding to the survey fell into three categories: services which were providing services to people with HIV and AIDS, services which were unsure that they were serving this particular population and services which were not providing services to this population. A range of services are being provided which include: direct medical care, psycho-social support, nutrition counselling, addiction counselling, home care, housing, income/financial support, food, clothing, and HIV prevention and education services. Respondents to the survey indicated that direct medical care and psycho-social support services were the most dominant services being provided to members of the community with HIV and AIDS. Many agencies indicated that HIV prevention and education services are a component of their service.

The most prominent gaps in service identified by respondents were the need for psycho-social supports and home care services. When asked of the willingness in organizations to develop or expand services needed the response was lukewarm. When asked to note what would be required to create new or expand existing services respondents noted funding as the most critical ingredient needed. Perceived difficulty in securing funding would appear to explain reluctance to develop or expand services for people with HIV and AIDS.

The report concludes that Hamilton should continue to develop services for people living with HIV and AIDS, that barriers to developing services should be examined and that continued work among service providers, planners, funding bodies and governments would be useful in addressing service needs.

1.0 INTRODUCTION

The Community AIDS Initiative is a project designed to improve access to relevant information and services for people living with HIV / AIDS and their caregivers. The Community AIDS Initiative in Hamilton-Wentworth is funded through the AIDS Community Action Program of Health Canada. The project activity is guided by a steering committee of representatives from the local health and social service agencies that provide HIV / AIDS related services and consumers of service. In the spring of 2000, a survey was carried out to gather information that would assist in the ongoing work to improve access to HIV / AIDS services in the community.

This report describes the results of the survey of human service providers in the Hamilton-Wentworth Region. The survey builds on the work done by the Regional AIDS Advisory Committee and the needs assessment they conducted in 1996. At that time consumers and service providers were surveyed in order to determine the range of available HIV / AIDS services and to identify gaps in service. Since 1996 there have been a number of changes in services, developments in medical treatments and epidemiological shifts which have indicated changing needs for HIV / AIDS services. This survey was carried out to gather up-to-date information on current service trends and needs for people living with HIV / AIDS and their caregivers.

2.0 BACKGROUND

The Human Immunodeficiency Virus (HIV) is the virus that causes Acquired Immunodeficiency Syndrome (AIDS). HIV attacks the immune system, resulting in a chronic, progressive illness and leaving infected people vulnerable to opportunistic infections and cancers. The median time from infection to AIDS diagnosis now exceeds 10 years. AIDS is fatal.

HIV is transmitted through:

- unprotected sexual intercourse
- needle-sharing
- an infected mother to an infant during pregnancy, delivery and through breast feeding
- occasionally through occupational exposure in the health care setting.

The HIV/AIDS epidemic is actually several epidemics, occurring in specific populations. Although these epidemics spread at different rates, the social factors and conditions which lead to the spread are similar. The virus itself changes quickly, mutating, creating new strains which present challenges in detection, prevention and treatment. No cure or vaccine exists. New treatments are very costly and it is too soon to measure their full effect (Health Canada, 2000).

Health Canada has noted that the first case of AIDS in Canada was reported in 1982. As of December 31, 1999, 16,913 AIDS cases have been reported to Health Canada. The total number of AIDS cases that have occurred in Canada since the epidemic began is estimated to be close to 20,000 (after adjusting for under-reporting and reporting delay).

Largely due to improved drug and therapy programs, the reported number of AIDS cases in Canada since 1995 is steadily declining. At the same time, Health Canada notes there are disturbing new trends. During the first half of the 1990s, infections decreased among men who have sex with men but increased among injecting drug users and women. Men having sex with men accounted for 53.4% of new positive tests in Canada during 1995-96, compared to 81% before 1995. Positive HIV test reports attributed to intravenous drugs users increased from 8.9% during 1985-94 to 29.8% in 1995 and 33.8% in 1996. Before 1995, adult women represented 9.6% of all positive HIV test reports with known age and gender in Canada. This proportion increased to 18.5% in 1995 and 20.4% in 1996.

Since 1996, the epidemic has shifted again. According to national HIV estimates produced by Health Canada, about 4,200 new infections occurred in Canada in both 1996 and 1999, but the composition of these new infections was quite different between the two years. In 1996, men having sex with men accounted for an estimated 30% of the 4,200 new infections, while intravenous drug users accounted for 47% and heterosexuals for 17%. In 1999, the men having sex with men proportion had increased to 38%, intravenous drug users had decreased to 34%, and the heterosexual group increased slightly to 21%.

The number of persons living with HIV in Canada is rising, from an estimated 40,000 in 1996 to 50,000 in 1999. In the case of AIDS, analysts are concerned that the decline in the annual number of new cases has leveled off since 1997.

Canada's National Task Force on HIV, AIDS and Injection Drug Use reported the following in 1997:

HIV rates in Canada are still increasing, with the infection spreading in vulnerable populations.

Canada is estimated to have had between 19,000 and 20,000 AIDS cases at the end of 1996 (adjusted for reporting delays and underreporting), with 72% of cases reported as having already died. Another 10,000-12,000 cases are expected by the year 2000. In terms of HIV, by the end of 1994, Canada is estimated to have had between 42,500 and 45,000 cumulative cases. Each year adds an additional 2,500 to 3,000 new cases.

Those becoming infected with HIV are younger. The median age of new HIV infection has dropped from age 32 years in those infected before 1983, to 23 in the period 1985-1990. It is clear that HIV is increasingly a problem of Canada's youth.

HIV among injection drug users is increasing dramatically. Although only 8.2% of cumulative AIDS cases reported to date are among injection drug users, the proportion of cases has increased over time, particularly for women. While 6% of cases before 1989 could be attributed to intravenous drug users, this figure rose to 15% between 1989 and 1992, and to 24% between 1993 and 1996. For men, the figures rose from 1%, to 2.6% to 5%, for the same time periods.

HIV data are of greater concern. In Ontario, prior to 1995, 2.8% of new positive tests were intravenous drug users. This has more than doubled to 6.1% in 1995.

New infections of HIV are occurring at a rapid rate among intravenous drug users. The spread of HIV through the general population in Canada is facilitated by injecting drug practices and it is of increasing concern.

Incarceration is a risk factor for acquiring HIV, with few innovations being implemented which would improve the situation. The legal aspects of drug use, and their intersection with HIV/AIDS, have created an emergency situation in Canadian prisons. Many injection drug users spend time in prison settings, either directly, because of drug convictions, or due to other criminal convictions related to that use. Between April, 1994, and August, 1995, the number of known cases of HIV/AIDS in federal correctional institutions rose by 40%.

Despite limited information, existing data indicate Aboriginal peoples are over-represented in groups most vulnerable to HIV infection. Aboriginal people, for a number of reasons, are often over-represented in many of the groups most vulnerable to HIV risk including inner-city populations, sex-trade workers and incarcerated individuals. Within our prison settings, 14% to 40% of inmates are Aboriginal (depending on the province), placing them at increased risk within this confined environment, in which the incidence rate is high. As well, many Aboriginal people move back and forth between urban settings and reserves, further increasing the potential for spread of HIV.

Women represent an increasing percentage of new HIV cases, many contracting the infection through injection drug use. The proportion of AIDS cases among adult women, as compared to all adult cases, has increased significantly, from about 5.5% during 1981-1989 to 7.2% during 1993-1996. Injection drug use accounts for 17% of all cases, second only to heterosexual transmission. As of September, 1996, 116 AIDS cases have been attributed to prenatal transmission. An increasing percentage of women being tested for HIV are being found to be positive. Prior to 1995, about 8.5% of women tested in Ontario were HIV positive, compared to about 16.4% in 1995. Key risk-factors are injection drug use, and having sexual partners who are at increased risk for HIV.

Canada's National Task Force on HIV, AIDS and Injection Drug Use notes the cost of inaction will outweigh the cost of response, in dollars, and in human suffering.

It is expected that treatment costs will increase as new drugs become available, and are used for longer periods of time. The costs of this crisis are enormous. In addition we must also consider the pain and suffering of persons living with HIV and AIDS, and the loss and grief experienced by family and friends.

New drug-using trends can affect HIV rates significantly. Attention has typically been focused on the heroin-using population, but new trends indicate an increasing shift toward cocaine use in many cities across the country. This raises the prospect of a broader range of networks for HIV transmission through both heroin and cocaine-using populations.

When people who inject drugs successfully stop injecting, it is important to have them regain a productive life without drugs. For this to happen, we must have opportunities for them to remain healthy.

Injection drug users do not live in isolation from the world around them. They are members of the community and, both during and after the periods of their lives, which involve the injection of drugs, they may form intimate partnerships and have children. Consequently, their experience and condition of health will affect many lives, potentially infecting and affecting many people who have never used drugs.

Again Canada's National Task Force on HIV, AIDS and Injection Drug Use reminds us "there are effective strategies that have been documented and can be implemented, and there are new paths to explore. Drug users can and do learn to use safer methods of injecting which can protect them, their partners, and their children from HIV. Some stop using drugs altogether. The right interventions, offered at the right time, do work." *(much of the information included in this section was obtained from "Epi Updates", Laboratory Centre for Disease Control, Health Canada, December, 1996.)*

The Health Issues Report 2000 for the City of Hamilton and Region of Hamilton-Wentworth reported that "there were 11 new HIV infections reported in H-W in 1999 compared to 12 in 1998 and 23 in 1997. Among the 11 new cases, there were more males than females."

The most common reported risk factor for contracting HIV in Hamilton-Wentworth were, for males, having sex with a male partner, and for females, having sex with an HIV positive male partner.

There were six new cases of AIDS reported in Hamilton-Wentworth in 1999 compared to seven in 1998 and five in 1997. Among the six new cases in 1999, there were more males than females. Two thirds of new AIDS cases were between the ages of 30 to 39 years."

The following table notes the number of AIDS deaths recorded for the Hamilton-Wentworth community over an eleven-year period from 1987 to 1997. For comparison it also provides this information for neighbouring communities. This record indicates that the death rate per 100,000 population over this period of time in Hamilton is comparable to the rates in Halton and Niagara, it is quantitatively different from the death rates in Toronto.

Table 1: AIDS Deaths in Ontario Counties: 1987-1997

	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	11 yr total	11 yr rate
Hamilton-Wentworth	8	9	8	11	6	12	16	20	10	15	10	125	2.43
Toronto	121	165	205	209	289	342	370	349	416	284	116	2866	10.89
Halton	7	7	6	6	5	9	3	7	12	5	3	70	1.94
Niagara	3	3	5	9	13	8	13	16	9	8	4	91	2.04

Source: Vital Statistics, Office of the Registrar General, from PHPDB, Feb 2000

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The 1996 report "*HIV / AIDS Community Services in the Regional Municipality of Hamilton-Wentworth: Addressing Needs Through Community Input*" describes the results of a study designed to focus on identified needs and community preferences for addressing needs. Using qualitative research methods, eight key informants identified and interviewed to gather the perspectives of individuals infected and affected by HIV / AIDS and the perspectives of service providers. The research focussed on three specific areas: experiences with community service provision, issues the service network should respond to and recommendations concerning community services needs. Of particular interest are recommendations offered on service trends and community needs as these essential questions are examined in the current study.

Of the thirty-nine recommendations made, several dealt with trends and needs. Although sometimes competing specific recommendations are offered, important common themes emerge. Among those are recommendations calling for increased coordination of services, more collaboration across health care specialties, use of a case management model and improved benefit programs for health and drug costs. Recommendations from the study also suggested improvements in the continuum of care services to respond to needs of people including a hospice or hospices to better serve people with AIDS. The expansion of the continuum of care also included recommendations to improve the availability of social assistance, better meet the transportation needs of individuals with HIV / AIDS, increase access to information through a 'hotline', increase the involvement of volunteers in the provision of services. The report also recommended an increase in the available hours of services, expanding programs such as the needle exchange program and food bank services as well as conducting more outreach particularly to intravenous drug users and young people. These recommendations provided a basis for the work of the Regional AIDS Advisory Committee in prioritizing and planning for the future.

Despite clear indications of an escalating problem in Canada since the mid-1980s and the use of a variety of approaches to address it, the spread of HIV among drug users is increasing, as is the incidence of hepatitis and tuberculosis. Epidemics continue to emerge among new populations. Intersecting issues-HIV and AIDS, substance use, mental health -create multiple problems in an individual for which there is no prescribed course of intervention or treatment."

They also report that intravenous drug use is not the only connection between HIV, AIDS and substance use. Alcohol and other drug use can alter judgement and adversely affect the adoption of safer sex practices, leading to an increased risk of contracting HIV. They suggest that continuing marginalization and stigmatization of drug users, especially those who inject, and those who are HIV positive or have AIDS, remain barriers to progress. These represent important community trends for service providers to consider in addressing trends and needs in the Hamilton community.

3.0 METHODOLOGY

The Community AIDS Initiative project members, in consultation with the Social Planning and Research Council of Hamilton-Wentworth, designed a mail-out questionnaire, which was sent to community service providers. (see Appendix) The survey instrument was introduced to respondents by a covering letter from the Chairperson of the Community AIDS Initiative explaining the purpose of the survey and encouraging response to the survey.

The surveys were sent out to one hundred and fifteen (115) agencies in May 2000 and responses to the survey were asked to be returned within two weeks. One follow-up phone call was committed to in order to encourage and increase response rates for the survey. Of those, 3 surveys were returned unopened with no indication as to an alternative point of contact. The remaining 112 surveys reached the targeted agencies.

The responses were collected by the Community AIDS Initiative and provided to the Social Planning and Research Council for analysis. The SPSS program was used to tabulate and analyze the data collected from survey responses. A report of survey results was written by the SPRC and returned to the Community AIDS Initiative for their use and circulation.

4.0 SURVEY RESULTS

Sixty-one responses were received providing a response rate of 54% to the survey. Each survey response provided the name of the agency returning the survey, the name of the person completing the survey, the job title of the person responding as well as the agency's business address and phone number. This information was useful in maintaining an up-to-date data base of organizations and agencies providing services to people living with AIDS and their caregivers in the Hamilton-Wentworth Region.

5.0 AGENCY SERVICE

Respondents were asked to identify the primary function of their organization. Ten service options were offered for respondents to choose from and a final option (other) which allowed for respondents to name some other service not already noted. The results were as follows:

Table 2: Primary Services

Primary service	Number of responses	Percent of responses
Nutrition counselling	2	3.3%
Clothing	2	3.3%
Income/financial support	2	3.3%
Food	3	4.9%
HIV Prevention & Education	4	6.6%
Housing	4	6.6%
Addictions counselling	5	8.2%
Home care	6	9.8%
Psycho-social support	8	13.1%
Direct medical care	13	21.3%
Other	18	29.5%

The 'other' category generated a strong response rate. Respondents to the survey were asked to name or define the other service that they were providing.

The following services were noted (responses are recorded as provided):

- Assistance for people with handicaps
- Bereavement self help support
- Case coordination, elderly, chronically ill, disabled clients
- Coordination of a range of health and support services
- Counselling and community support services, residential care for unwed mothers
- Emergency shelter
- Family planning standard and healthy sexuality counselling
- Funeral service
- Immigrant/refugee chiropody, physiotherapy, health promotion initiative
- Legal services

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- Family planning standard and healthy sexuality counselling
- Funeral service
- Immigrant/refugee chiropody, physiotherapy, health promotion initiative
- Legal services

- Mediation counselling
- People in conflict with the law
- Providing legal advice and representation to low income residents
- Safe shelter and abuse education and counselling
- Spiritual guidance, Christianity
- Volunteer visiting /pay hospice
- Women's health

6.0 SERVICES

6.1 Service to HIV/AIDS Population:

The survey then asked respondents if their organizations were providing services to people with HIV / AIDS. Thirty-six respondents indicated that they were clearly providing services to people with HIV / AIDS, one respondent indicated their organization did not provide services to this population and 10 respondents indicated they were unsure as to whether or not they were providing services to this population.

Of those who responded yes to the question of providing services to people living with HIV / AIDS, they were asked in a follow-up question to specify which services their agency provided and to rank them in order of most provided to least provided. Again ten possible service options were named for respondents to choose from as well as an 'other' category for services not named in the list.

The results for each service option were:

HIV Prevention and Education: Seventeen (17) organizations identified HIV prevention and education as a component of their services. Of those, six (6) identified this as their highest priority in providing services.

Direct Medical Care: Eight (8) organizations identified direct medical care as a component of their services. Of those, seven (7) identified this as their highest priority in providing services.

Nutrition Counselling: Four (4) organizations identified nutrition counselling as a component of their services. Of those, three (3) identified this as their highest priority in providing services.

Addiction Counselling: Five (5) organizations identified addiction counselling as a component of their services. Of those, three (3) identified this as their highest priority in providing services.

Psycho-social Support: Eleven (11) organizations identified psyco-social support as a component of their services. Of those, four (4) identified this as their highest priority in providing services.

Home Care: Seven (7) organizations identified home care as a component of their services. Of those, four (4) identified this as their highest priority in providing services.

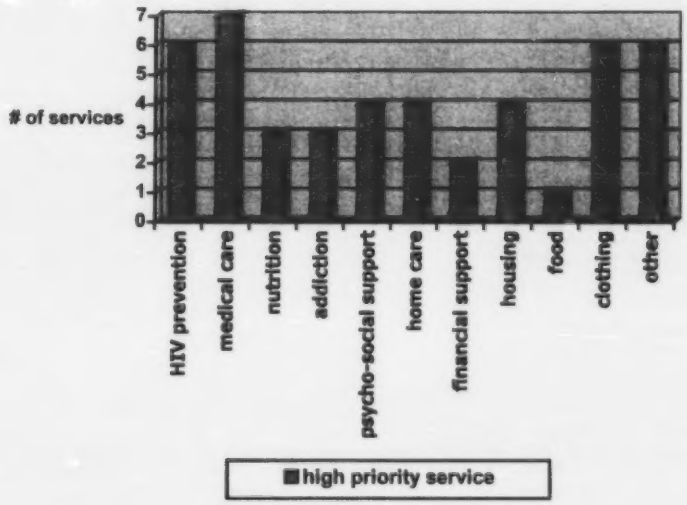
Income / Financial Support: Four (4) organizations identified income / financial support as a component of their services. Of those, two (2) identified this as their highest priority in providing services.

Housing: Five (5) organizations identified housing as a component of their services. Of those, four (4) identified this as their highest priority in providing services.

Food: Three (3) organizations identified food as a component of their services. Of those, one (1) identified this as their highest priority in providing services.

Clothing: Six (6) organizations identified clothing as a component of their services. All six (6), identified this as their highest priority in providing services.

Figure 1: Highest Priority Service



The chart titled High Priority Services illustrates the distribution of services that are considered to be the main focus of agencies responding to the survey.

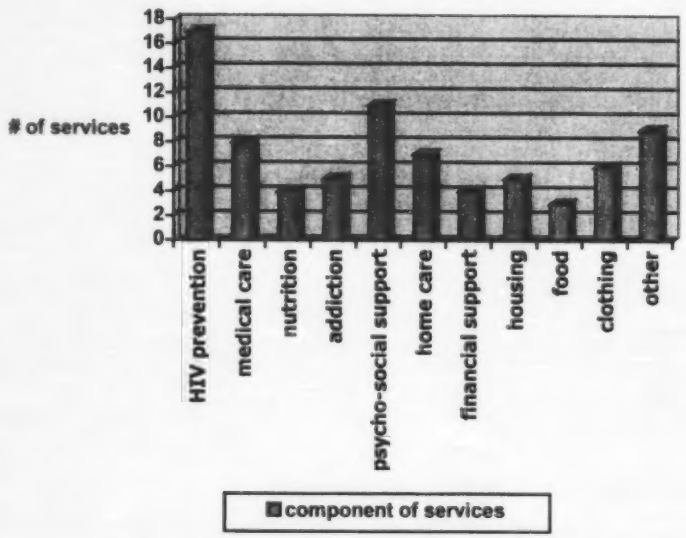
Other: Nine (9) organizations identified other as a component of their services. Of those, six (6) identified this as their highest priority in providing services.

In the case of this final option for 'other' service, respondents were asked to

name the service. Their responses included the following:

- Bereavement counselling to surviving partners and family members
- Case management
- Day hospice
- Disability appeal
- Information and referral
- Legal services
- Referral for addictions and traditional aboriginal healing services
- Research
- Social interaction
- Spiritual guidance (Christianity)
- Volunteer visiting, meals on wheels

Figure 2: Components of Agency Service



The chart titled Components of Agency Services illustrates the distribution of services that are considered to be available but a secondary interest of agencies responding to the survey.

6.2 Services Specific To HIV / AIDS Population

Respondents were asked to indicate if any of the services being provided by their organization were designed specifically to meet the needs of people living with HIV / AIDS.

In answer to this question, 13 respondents (21%) noted their services were specific to the HIV /AIDS population, while 27 respondents (44.3%) noted their services were designed for a wider population.

For those respondents indicating that some or all of their services were designed specifically to meet the needs of people living with HIV / AIDS, they were asked to better identify those services by naming them. The following services were named as specific to the HIV / AIDS population (note that responses are reported exactly as provided by respondents):

- HIV prevention and education, direct medical care, nutrition counselling
- All of the above named support services are offered only to families living with HIV and are the needs voiced by our clients
- Bereavement counselling tailored to individual circumstances and needs
- Only in terms of providing resources, information
- Direct medical care, HIV prevention counselling and education, especially with teens and high risk people
- Direct medical care, prevention and education
- Do have a nurse who has extensive education and experience in nursing individuals with AIDS
- Each service is non-judgmental and non-bias; we provided food and spiritual help unconditionally
- H.A.N. provides all services to residents with AIDS
- Medical care of children with HIV follow infants of HIV and mothers
- Nursing services and client education; our model is client centred so each client's care is individualized according to their diagnosis and needs
- Referral to CCAC, referral to community resources
- Referrals, support, harm reduction
- Regular follow-up and treatment of abnormal Pap tests for cervical cancer

5.3 Accessing HIV / AIDS services

Respondents were asked to indicate how persons living with HIV /AIDS access services. Six options were offered for respondents to choose from, the last of these was an 'other' option. If selected, respondents were asked to specify that form of access. The results to this question are recorded in the following table:

Table 3: Access to Services

Access type	Number of responses	Percent of responses
Telephone	38	62.3%
Referrals	37	60.7%
Office visit	28	45.9%
Home visit	19	31.1%
Drop-in centre	2	3.3%
Other	11	18.0%

Respondents who indicated that there were other ways to access their services than the options noted, provided the following information on alternative access methods:

- Community Housing Registry processes applications for Hamilton
- Hamilton AIDS Network provides residents to dedicated units
- 24 crisis line
- as requested
- by accessing any services provided by Good Shepherd Centres, no referral or appointment required
- CCAC
- Has to understand French since it is the language of service at the Centre
- Housing application to the Coordinated Housing Access Network and completion of special needs form
- Must be native or non-native partner of native person, do not have to have status
- Must be patients of our centre
- Outreach worker, Ruth Groenspan, can be reached at extension 32
- Self referral, must be a patient of the centre
- Self referral, clergy, social worker
- Store visit

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- Self referral, must be a patient of the centre
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6.4 Gaps in Services

The survey then asked respondents to identify gaps in HIV services that should be addressed. The question named eleven service areas to choose from and for each of those offered a Likert scale ranging from very important to not important to assist in analyzing the priority for addressing gaps in services.

Respondents were also offered an "other' category which would allow them to name a gap in service not noted in the options provided. Respondents could also rank this other service area in terms of its importance to address. The following table summarizes responses:

Table 4: Gaps in Services

Service area	% Responses Very important	% Responses Important	% Responses Somewhat important	% Responses Not very important	% Responses Not at all important	Total responses %
Home care (nursing, homemaking)	34.4%	8.2%	0	0	0	42.6%
Psycho-social support	31.1%	11.5%	1.6%	0	0	44.3%
HIV prevention & education	27.9%	8.2%	1.6%	0	0	37.7%
Housing	24.6%	13.1%	1.6%	1.6%	0	41%
Direct medical care	23.0%	9.8%	1.6%	0	0	36.1%
Income/financial	21.3%	14.8%	6.6%	0	0	42.6%
Nutrition counselling	21.3%	14.8%	1.6%	0	0	37.7%
Food	18.0%	11.5%	8.2%	0	0	37.7%
Addiction counselling	18.0%	18.0%	4.9%	0	0	41.0%
Transportation	16.4%	18.0%	4.9%	1.6%	0	41%
Clothing	3.3%	11.5%	11.5%	6.6%	0	32.8%

Approximately ten percent of responses to this question identified the 'other'

6.4 Gaps in Services

The survey then asked respondents to identify gaps in HIV services that should be addressed. The question named eleven service areas to choose from and for each of those offered a Likert scale ranging from very important to not important to assist in analyzing the priority for addressing gaps in services.

Respondents were also offered an "other' category which would allow them to name a gap in service not noted in the options provided. Respondents could also rank this other service area in terms of its importance to address. The following table summarizes responses:

Table 4: Gaps in Services

Service area	% Responses Very important	% Responses Important	% Responses Somewhat important	% Responses Not very important	% Responses Not at all important	Total responses %
Home care (nursing, homemaking)	34.4%	8.2%	0	0	0	42.6%
Psycho-social support	31.1%	11.5%	1.6%	0	0	44.3%
HIV prevention & education	27.9%	8.2%	1.6%	0	0	37.7%
Housing	24.6%	13.1%	1.6%	1.6%	0	41%
Direct medical care	23.0%	9.8%	1.6%	0	0	36.1%
Income/financial	21.3%	14.8%	6.6%	0	0	42.6%
Nutrition counselling	21.3%	14.8%	1.6%	0	0	37.7%
Food	18.0%	11.5%	8.2%	0	0	37.7%
Addiction counselling	18.0%	18.0%	4.9%	0	0	41.0%
Transportation	16.4%	18.0%	4.9%	1.6%	0	41%
Clothing	3.3%	11.5%	11.5%	6.6%	0	32.8%

Approximately ten percent of responses to this question identified the 'other'

option as worth noting. Each respondent identified different service gaps that need to be addressed. The gaps noted included the following:

- Caregiver support
- Development of methadone treatment programs
- Limited incomes, marginal lifestyle, little or no family support
- Back to work rehab facilitator
- Therapeutic therapies
- easy access to needle exchange
- In-house residence

Several respondents indicated in their comments to this question on the survey that they were unsure of gaps in service areas outside of their particular service area. The reason noted was a lack of information. A couple of respondents noted that all the service areas named were important and would impact on a person's social, financial and spiritual well-being.

6.5 Developing services

The next question in the survey asked respondents to indicate what services their organization would like to develop or expand for persons living with HIV / AIDS. Again the question named eleven service areas to choose from and for each of those offered a Likert scale ranging from very important to not important to assist in analyzing the priority for developing services by existing service providers. Respondents were also offered an "other" category which would allow them to name a service not noted in the options provided. Respondents could also rank this other service area in terms of its importance to develop.

The following table summarizes responses.

Table 5: Services to Expand or Create

Service area	Responses Very important	Responses Important	Responses Somewhat important	Responses Not very important	Responses Not at all important	Responses missing
Psycho-social support	14	2	1	0	0	44
HIV prevention & education	11	2	1	1	0	46
Direct medical care	8	2	1	0	0	50
Addiction counselling	8	2	0	1	0	50
Home care (nursing, homemaking)	6	2	2	0	1	50
Nutrition counselling	5	3	1	0	0	52
Food	2	2	3	1	1	52
Transportation	1	2	2	2	1	53
Housing	1	1	4	0	1	54
Income/financial	1	4	0	0	1	55
Clothing	0	0	3	2	1	55

There were eight respondents to this question who identified other service options as important and services, which they would like to develop. The 'other' services to be developed were described as:

- Abuse education, information, support
- Increased space for emergency night shelter
- Bereavement support
- Caregiver support
- Day programs
- Home maintenance program for those living in the community with illness or disability
- Increase outreach in bars and foot outreach
- Bring another methadone clinic to Hamilton

- Referrals
- Work rehab and methadone

6.6 Organization requirements for new services

Respondents were asked to indicate what their organization would require to provide the new or expanded services noted in the previous question. Several options were given from which respondents could select. These options were offered based on the knowledge and experience of the survey designers as frequent and familiar considerations in developing any new community service. However the options offered were not exhaustive, so respondents were also invited to name other requirements necessary to providing new or expanded services. The following table summarizes responses.

Table 6: Requirements for New Services

Service area	% Responses Very important	% Responses Important	% Responses Somewhat important	% Responses Not very important	% Responses Not at all important
Funding	27.9%	4.9%	4.9%	1.6%	0
Education	26.2%	8.2%	1.6%	1.6%	0
Personnel	19.7%	8.2%	3.3%	1.6%	0
Space	13.1%	3.3%	4.9%	1.6%	1.6%
Mandate	9.8%	0	3.3%	3.3%	0

Three respondents indicated that other supports were required to provide new or expanded services. They specifically noted the following requirements:

- A number of clients with interest or affliction
- Community partners
- Identified need for the service
- Information

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Service area	Responses Very important	Responses Important	Responses Somewhat important	Responses Not very important	Responses Not at all important	Responses missing
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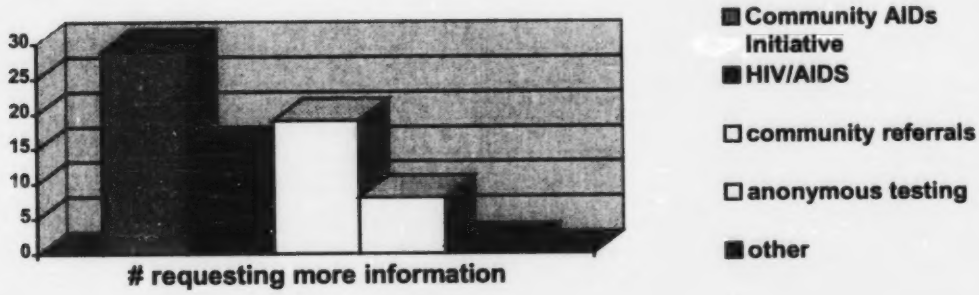
Three respondents indicated that other supports were required to provide new or expanded services. They specifically noted the following requirements:

- A number of clients with interest or affliction
- Community partners
- Identified need for the service
- Information

7.0 INTERESTED IN RECEIVING MORE INFORMATION

The survey asked respondents to indicate if they would like to receive more information on these subjects: community AIDS Initiative, HIV/AIDS, community referrals, anonymous testing or some other subject they could name. The results are reported in the following graph:

Figure 3 : Requests for More Information



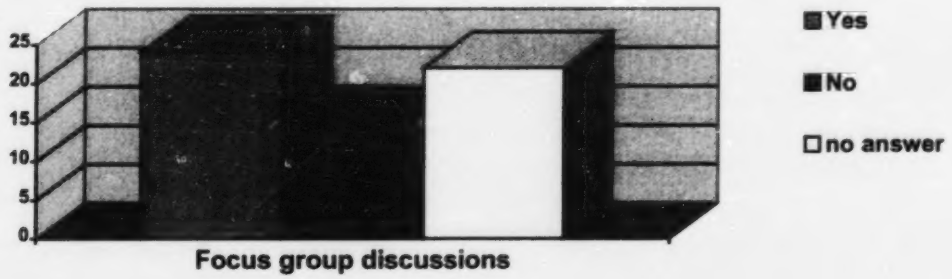
Respondents were asked if they would be interested in participating further in focus group discussions about access to services for persons living with HIV /AIDS. The following chart indicates the level of interest among respondents in this activity.

One respondent suggested that more information on drop-in centres operating in the community would be useful.

Interest In Focus Group Discussions

Respondents were asked to indicate their interest in participating in focus group discussions. The following chart indicates the level of interest among respondents in this follow-up.

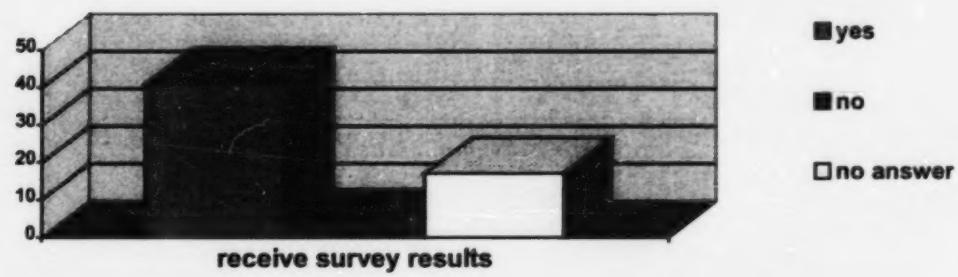
Figure 4: Interest in Focus Group Discussions



Interest In Survey Results

Respondents were asked to indicate their interest in receiving a summary of the results of the survey when they become available. The following chart indicates the level of interest among respondents in this follow-up. This result clearly shows that people in services would like more information.

Figure 5: Interest in Survey Results



8.0 CLOSING COMMENTS FROM RESPONDENTS

To complete the survey, respondents were invited to record any additional comments of interest. Sixteen respondents offered closing comments given this opportunity. The comments made were confined to reflecting service issues and included the following:

- In early stages of agency development, supporting access and providing culturally relevant care for aboriginal peoples
- High incidence of substance abuse in this population, Hepatitis C at 4%
- Referrals have come from the AIDS Network and so clients have support already in place to deal with specific issues
- Friends in Grief offers bereavement support, no one is turned away
- Let the HIV/AIDS community initiatives group know about our services so family members can attend would be useful
- The issue of space for services is very important for a drop in type clinic
- The spiritual needs of the people living with HIV /AIDS needs to be addressed through educating them, non-judgmental, non-biased support
- We are not aware if we provide service to those with HIV / AIDS as it is not mandatory that residents disclose that information
- Especially interested in HIV / AIDS from a gender based analysis
- Change in home care has brought a loss of expertise in palliative care
- Women are a neglected group in the receipt of services for people who are HIV / AIDS positive

9.0 ANALYSIS OF RESULTS

Responses to the survey were received by a wide range of service providers. The largest number of responses came from service providers categorized as providing direct medical care. The second best represented service category was that of psycho-social support service providers. Almost 30% of respondents didn't identify strongly with any one service type, suggesting a wider array of service providers than those ten service types identified in the survey. This would indicate that the results of the survey have captured a variety of perspectives offered by service providers on the current array of services available and needed in the community for people with HIV / AIDS.

When asked if their organizations were providing services to people living with HIV / AIDS almost 60% of respondents indicated they were serving this population. More than 16% of respondents replied they were not sure. This later group establishes that one of the difficulties in assessing service utilization patterns by the HIV / AIDS population when asking service providers is that they cannot always know the extent to which they are meeting the needs of this population.

Those services which were known to be serving people living with HIV / AIDS rated the different services in terms of those most provided. Direct medical care was most often identified as a primary or often provided service. The next most often primary service being provided by respondents was HIV education and prevention. Housing, home care and psycho-social support services were all well represented as primary services being provided.

Respondents were also asked to indicate when their organization was providing more than one primary service to people living with HIV / AIDS. The results indicate that many of the agencies responding to this question are providing a range of services to the population of interest. HIV prevention and education services were most often noted as a component of the range of services being provided by agencies. Psycho-social support was the second most often noted service being provided by agencies.

Services are targeted specifically for people living with HIV / AIDS in only 21% or one fifth of the agencies responding to the survey. Many more agencies, 44% , were providing service to a wider population of interest likely with more varied needs.

Access to service takes a variety of forms. In the majority of cases services are being accessed by telephone. Access to a service through referral is an almost equally used format for connecting with a service. The next most common way to access services would appear to be through a visit to the agency's office or service centre. Drop-in centres would appear to be a little used method for accessing service by people living with HIV / AIDS.

When asked to identify gaps in local services respondents indicated that psycho-social support services constituted the most obvious and important gap in services to note. Home care services were noted as an almost equally critical gap in service. The need for income and financial supports was also highly ranked as an important gap in the service system. Housing, addiction counselling and transportation were seen as the next most critical gaps in services. It is worth noting that all eleven service areas named in the question received strong response indicating that all represented a significant service area, which can be associated with gaps in services.

When asked if there were services that organizations would like to develop or expand in view of identified gaps in service, service providers were very selective when indicating which services they would be prepared to attempt to expand or create. In each service category, 80% to 90% of respondents indicated they would not attempt creating a particular service. Still, creating or expanding psycho-social support services drew the strongest positive response, HIV prevention and education was also well supported and direct medical care and addiction counselling also appeared to have willing sponsors for expanding or creating new services. No service category was without at least one or two service providers willing to make some attempt to expand or create a new service where needed, although in several cases the enthusiasm was decidedly lukewarm.

The next question asked what would be required to provide the expanded services. The responses to this question provide some insight as to why service providers might be reluctant to attempt developing new services.

Funding was identified most often as the critical ingredient need in order to provide new or expanded services. Almost surprising was the response to education as a nearly equally critical ingredient to developing services. Finding the personnel necessary to deliver the service was the third most necessary requirement for creating services that respondents identified.

Respondents indicated a strong interest in receiving more information on the Community AIDS Initiative, HIV / AIDS, community referrals process and anonymous testing. The interest noted may well be enough to justify further work to inform service providers of activity and issues in these subject areas.

Although the majority of respondents did not indicate having an interest in participating in focus groups as a follow up to this survey, a substantial number of respondents (24) indicated an interest in this activity. This group may be useful to identify and bring together for the purpose of discussing in more depth some of the findings noted as a result of the survey.

The majority of respondents indicated they would like to receive a summary of the survey results. It would be appropriate to send a brief report of findings to all respondents for their information.

10.0 SUMMARY AND CONCLUSION

This survey has established that there are a number of concerns among service providers about the need for continued development and expansion of services to people living with HIV / AIDS. Psycho-social supports, home care services and income and financial supports top the list of areas in need of development.

A number of agencies have indicated some interest in exploring further the prospect of being a part of developing services where needed. In addition, barriers to developing services are clearly funding, education and qualified personnel. Given this interest and sense of the barriers it may be useful for service providers to meet with planners, funding bodies, education institutions and employment services to discuss the potential for better understanding the needs and potential for solutions to service needs of people living with HIV / AIDS.

SELECTED REFERENCES

Hamilton-Wentworth Regional AIDS Advisory Committee. (1996). HIV/AIDS Community Services in the Regional Municipality of Hamilton-Wentworth: Addressing Needs Through Community Input. Hamilton, Ontario

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Ministry of Health. (1998). The National AIDS Strategy Minister of Public Works and Government Services Canada; Ottawa, Canada

Minister of Health. (1998). Renewing Canada's Strategy on HIV and SIDS: Successes, Barriers and Lessons Learned. Minister of Public Works and Government Services Canada; Ottawa, Canada.

Good Shepherd Centres

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905-528-9109

Mending Hope, Lives and Families
** Charity Unlimited**

COMMUNITY AIDS INITIATIVE
35 AIKMAN AVENUE
HAMILTON, ONTARIO
L8M 3M8

May 10, 2000

Dear Service Provider

The Community AIDS Initiative is a project funded through the AIDS Community Action Program, Health Canada. This project is guided by a steering committee comprised of representatives from local health and social service agencies, especially those which provide HIV/AIDS-related services. The mandate of the project is to improve access to relevant information and services for people living with HIV/AIDS (PHAs) and their caregivers.

The Community AIDS Initiative project arose from a needs assessment that was commissioned by the Regional AIDS Advisory Committee in 1996. At that time, consumers and service-providers were surveyed in order to determine the range of available HIV/AIDS services in Hamilton-Wentworth, with the goal of identifying gaps in service. Since 1996, significant developments in medical treatments, along with epidemiological shifts, have resulted in changing needs for HIV/AIDS services. In the year 2000, the Community AIDS Initiative project would like to ensure that HIV/AIDS services in our communities keep pace with these changes.

We are looking for your assistance. The Questionnaire for Service Providers, enclosed, will assist the Community AIDS Initiative in assessing the inventory of current services in the Hamilton-Wentworth region. This will be the first step in the work to improve access to HIV/AIDS services in our communities. All answers will be collated and presented in aggregate form. The results will be released in a report in 2001.

Please take a few minutes to complete the enclosed survey and return it to Alda Grigaitis (Project Coordinator) at Good Shepherd by May 31, 2000.

If you have any questions regarding this correspondence or the Community AIDS Initiative project in general, then please contact Alda Grigaitis at (905) 525-5188 extension 27.

Thank you for helping us to improve HIV/AIDS services in our communities.

Sincerely,

D. Williams

Duane Williams
Chairperson, Community AIDS Initiative

Good Shepherd Centres

135 Mary Street, Box 1003
Hamilton, Ontario, L8N 3R1
905-528-9109

Mending Hope, Lives and Families
** Charity Unlimited**

COMMUNITY AIDS INITIATIVE

35 Aikman Ave.
Hamilton, Ontario
L8M 3M8
fax # (905) 525-2366

QUESTIONNAIRE FOR SERVICE PROVIDERS
REGARDING SERVICES FOR PERSONS LIVING WITH HIV/AIDS

Please fill out this questionnaire and return by mail or fax, attention Alda Grigaitis, before May 31th, 2000. We will be following up by phone on June 15, 2000. Thank you.

Individual responses to this questionnaire will not be reported or recorded. All information will be reported in aggregate form only.

Name of agency/organization/business:

Name of person completing this survey:

Title:

Address:

Phone number:

1. What is the primary function of your organization? (Check one)

HIV Prevention & Education	❑
Direct Medical Care	❑
Nutrition Counselling	❑
Addictions Counselling	❑
Psycho social Support	❑
Home Care (nursing, homemaking, etc.)	❑
Housing	❑
Food	❑
Clothing	❑
Income/Financial Support	❑
Other	❑ (Please name)

2. a) Are you providing services to people living with HIV/AIDS?

Yes ❑ No ❑ Unsure ❑

b) If yes, please specify which services you provide to persons living with HIV/AIDS? (Please rank in order of service most provided, with 1 being service most provided)

HIV Prevention & Education	___
Direct Medical Care	___
Nutrition Counselling	___
Addiction Counselling	___
Psycho social Support	___
Home Care (nursing, homemaking, etc.)	___
Income/Financial Support	___
Housing	___
Food	___
Clothing	___
Other	___ (Please name)

c) Are any of these services designed specifically to meet the needs of people living with HIV/AIDS?

Yes ❑ No ❑

Please name services:

d) How can persons living with HIV/AIDS access your services?

By telephone	❑
Office visit	❑
Home visit	❑
Drop-in Centre	❑
Referral	❑
Other	❑ (Please name)

3. What gaps in HIV services in Hamilton-Wentworth should be filled (perhaps by another service organization or c: provider)? Please circle.

Housing	very important	important	somewhat important	not very important	not at all important
Transportation	very important	important	somewhat important	not very important	not at all important
Psycho social support	very important	important	somewhat important	not very important	not at all important
Income/Financial	very important	important	somewhat important	not very important	not at all important
Food	very important	important	somewhat important	not very important	not at all important
Direct Medical Care	very important	important	somewhat important	not very important	not at all important
Clothing	very important	important	somewhat important	not very important	not at all important
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Home Care (nursing, homemaking, etc.)	very important	important	somewhat important	not very important	not at all important
Nutrition Counselling	very important	important	somewhat important	not very important	not at all important
Other (Please name)	very important	important	somewhat important	not very important	not at all important

4. What services, if any, would your organization like to develop or expand for persons living with HIV/AIDS? Please circle.

Transportation	very important	important	somewhat important	not very important	not at all important
Food	very important	important	somewhat important	not very important	not at all important
Housing	very important	important	somewhat important	not very important	not at all important
Psych social Support	very important	important	somewhat important	not very important	not at all important
Direct Medical Care	very important	important	somewhat important	not very important	not at all important
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Income/Financial	very important	important	somewhat important	not very important	not at all important
Other (please name)	very important	important	somewhat important	not very important	not at all important

5. What would your organization require to provide these services? Please circle.

Funding	very important	important	somewhat important	not very important	not at all important
Education	very important	important	somewhat important	not very important	not at all important
Personnel	very important	important	somewhat important	not very important	not at all important
Mandate	very important	important	somewhat important	not very important	not at all important
Space	very important	important	somewhat important	not very important	not at all important
Other (Please name)	very important	important	somewhat important	not very important	not at all important

6. Would you like to receive more information on:

Community AIDS Initiative ❒
HIV/AIDS ❒
Community referrals ❒
Anonymous testing ❒
Other (Please name) ❒

7. Would you be interested in participating further in focus groups regarding accessing services for persons living with HIV/AIDS?

Yes ❒ No ❒

8. Would you like to receive a summary of results of this survey when available?

Yes ❒ No ❒

Comments:

Thank you for your participation.